

Disability Visibility Podcast

Episode 44: Disabled Writers

Guest: Carly Findlay

Host: Alice Wong

Transcript by [Cheryl Green](#)

For more information: <https://disabilityvisibilityproject.com/podcast/>

Introduction

[radio static, voices singing with hip-hop beat]

LATEEF MCLEOD: This is the Disability Visibility Podcast with your host, Alice Wong.

ALICE WONG: Hello, all you lovely humans! Welcome to the *Disability Visibility Podcast*, conversations on disability politics, culture, and media. I'm your host Alice Wong. Today I talk with Carly Findlay, author of a new book titled *Say Hello* published by Harper Collins. Based in Melbourne, Australia, Carly is a blogger, writer, speaker, and appearance activist. We talk about her writing career, the politics and pitfalls of visibility, and her writing process for *Say Hello*. Please note: I interviewed Carly in 2018, as she was in the middle of writing her book. Also, *Say Hello* is currently available in Australia and New Zealand, but you can check Carly's website for the latest information at carlyfindlay.com.au/sayhello. Are you ready? Away we go! [electronic beeping]

ELECTRONIC VOICE: 5, 4, 3, 2, 1!

ALICE: So, Carly, thank you so much for being on my podcast today!

CARLY FINDLAY: Thank you for having me, Alice. We've been online friends for a while.

ALICE: Yes, many years. And I'm just delighted to be able to hear your voice and talk to you in this way.

CARLY: [chuckles]

ALICE: Why don't you introduce yourself and just share anything you'd like about your work and your background?

CARLY: Yeah, sure. So, I am a writer. I write my blog sometimes. I don't have much time for that anymore. I write for the media. And at the moment, I'm writing a book, which is taking up all of my time, and it's very busy. And it feels like this awful school assignment that's hanging over my head. I got two more days to go, and then I submit my second draft, which is good. And it will be out next year. In addition to my book and my writing, I am a speaker. So, again, I have to write speeches, and I talk to a lot of community groups and workplaces, sometimes schools. I provide regular training to a company. I also work for Melbourne Fringe Festival, which is a arts festival, and I'm the Access and Inclusion Coordinator. So, this is the first time a role like this has been in an arts organization or a festival organization in Australia, so that's quite exciting. I think that's it. I'm pretty busy all the time, and I'm tired.

ALICE: Yes, you're doing all kinds of media and all kinds of activism, and that's really exciting to be diversifying.

CARLY: Yes.

Carly's origins as a writer and blogger

ALICE: And before we talk about your book, I was wondering if we could talk a little bit about the origins of your work, especially your blog.

CARLY: Yeah!

ALICE: Because I think I first came across you through your blog either on Facebook or on Twitter, and how would you say your blog launched your career as a professional writer?

CARLY: I started many years ago, like in 2001 I would say. I was reading blogs well before that though. I was reading blogs since about 1998, maybe '99. And I started blogging in 2001 on a platform called Diaryland, and it was not very good. My blogs weren't very good. I guess in hindsight, they would be like tweets, like a couple of lines about what I was thinking, generally about like a boy that I was having a crush on or something. It wasn't hugely intellectual nor important, I guess! And I certainly never mentioned my disability. Back then, I didn't even identify with having a disability. even though I've had this skin condition for all of my life, I didn't really understand the definition of disability as per the Social Model, all of that stuff. So, didn't mention it, and I also never shared photos of myself online because I was worried about what would happen. You know, I was worried about being made fun of.

So, fast forward about, I don't know, to 2006 I would say. I'd had Myspace for a while, and I was writing some blogs. And I was also doing a Masters of Communication, and I was writing blog on Myspace. And lots of people who didn't use Myspace were saying, "I wish I could read your work." I kind of wrote a little bit more, I don't know, a little bit more topical stuff then, but still nothing about disability. I think I might've written a little bit if I was having a sore day but nothing huge. But I had just started to share my photos online then. I was getting a bit more trusting. And also, I was taking more photos of myself. Back in 2001 I wasn't. And I guess that comes with the advent of the smartphone as well, you know, that we're able to take a selfie really quickly or a photo really quickly.

And then so, I was doing my Masters, and with the request that I was not on Myspace anymore or wasn't to be on Myspace anymore and with my Masters, I thought oh, I have to develop some sort of portfolio of writing. And I think between 2001 and 2009, I had a number of different blogs: Diaryland, Myspace. I had one for university for a particular subject. I had some others. And then I started my blog at CarlyFindlay.blogspot.com, and I called it "Tune In to Radio Carly." The reason I called it that was because a friend at work said that I constantly change the subject: like I might be talking about things, and then I'll go into another subject. And then he kind of said one day, "Tune in to Radio Carly." So, I called it that, and it was funny because a lot of people who would pretend that they'd read my blog would say, "Oh, how's your radio show going?"

ALICE: Ah! [laughs]

CARLY: And I said, "I don't have a radio show." [laughs] So, I could tell that they were kind of being interested, but they hadn't actually read it. Because if they did, they'd know it wasn't a radio show. So, again, I was writing more topically on things that happened in the media or in society. And then one day—so, I started that in 2009—and in 2010, early in 2010, I had a really sore face, and I wrote a piece called *When My Face is This Sore, I Don't Want to Look in the*

Mirror. And that was the first time I really wrote about my skin condition and about disability, and it got such a good reception I thought oh, I should write a little bit more about myself. I should open up a bit more. And I wrote a bit more. I wrote about kind of the social barriers, particularly around dating. I wrote a lot about dating back then. And then I submitted my work to a government organization who was doing a disability website, and so I would write little stories like every month or so. And it was good money back then. I had a full-time job, worked for the government, and I was getting \$200 an article, \$200, \$300 an article. So, I wrote on there, but I found they were very constrained, and they would simplify the articles a lot.

One of the best things that happened through writing—or two of the best things that happened—I met my best friend, my now best friend ‘cause she was writing, and I kinda stalked her on Facebook and got in touch with her. I thought we have things in common. Let’s be friends. And the first time I met her was when she was in hospital. She was on the waiting list for a lung transplant, and she would write a lot about that. And I met her when she was sick in hospital. She’s since had a transplant. She’s five years on, and she was a bridesmaid at my wedding. So, that was good to come out of that website. And the other good thing was I wrote a piece on body image and disability, and I had contacted a woman who is very big in the media, although not very popular. And while I don’t read her website now and don’t like it, I will always be grateful for her push of me in the media, which was a big thing.

I won some blogging awards, which made me access some, which gave me access to some writing programs as the prizes. So, I did some—in addition to my Masters, which I finished in 2012—I did some courses online about how to pitch and how to write for magazines ‘cause I didn’t learn that stuff in my Masters of Communication. It was more about working in a newsroom, so they were really valuable. And then my first pitch for my assignment for that course, I got published on a website called Daily Life. Oh no. Actually, no, *frankie magazine*, which is a magazine. It’s very arty, cutesy in Australia. It’s been around for a long time. I got published in *frankie magazine*. I wrote my article. It was a big feature. That was on the day I graduated from my Masters, actually, so that was lovely. And then I pitched to Daily Life in 2013. So, I’d say in 2012, 2013, that was when I started writing properly for the media, and I have been ever since.

[upbeat music break]

Pitfalls and risks of being so visible and representing disability community

ALICE: What do you think are some of the pitfalls and risks of being so visible and having to represent all things for the disability community?

CARLY: Yeah. I mean I’ve definitely seen some really dark sides, particularly in the past year. I think that as my profile grows—and I kind of feel like I constantly have to justify this because I’ve had so much of a backlash to my work and my perceived success—but I feel like people just wait to chip you up, that you have to be perfect, and that you can’t, there’s no room to make a mistake. People will pounce on you. It can be really, really hard: both the feedback from disabled and non-disabled people can be hard. I find there’s a lot of pressure to be responsive to people. I had a really weird experience with a person who emailed me or messaged me through my Facebook page, my public Facebook page, and she said to me that she saw someone with a facial difference, and she doesn’t know how to respond. Because when she was younger, her mother told her to look away, and now she doesn’t know if she should look away or look at them and make eye contact and whatever. And I hadn’t responded because I was busy. And then the next night, around the same time, she wrote back to me to say, “Well, I guess your lack of response is your answer. I’m never talking to a person with a facial difference

again.” I’m like, whoa! I can’t be that person that sets the tone of how you’re gonna respond to a person with a facial difference.

I have parents sort of desperate, and they don’t even say hello. They’ll just send me photos of their child. There was one person that sent me photos of their child’s genitals to show me how bad the skin was. I’m like, “You don’t do that!” And then they get all apologetic, like, “Oh, I’m sorry if I offended you.” But it’s not about my offense; it’s about the fact that it’s wrong to share photos like that online.

I don’t think I’ve found my people like I have in the disability community, in the ichthyosis community, or not many of them anyway. I mean I’m really close to a few of them, but in terms of identifying with disability and disability rights, I don’t find that in the ichthyosis community. Yeah. And also, I’ve had a really awful case of online harassment and stalking, and you know, I went to court.

Self-protection and self-care

ALICE: And how do you protect yourself or I guess practice self-care for yourself? Because clearly, there’s a lot of burn-out. A lot of people are driven away from social media. So, how do you kind of, for the long-term goals of your own wellness and your own career, how do you take care of yourself?

CARLY: I don’t know. It varies. I mean there’s the kind of physical safety things where you might’ve saw on my Facebook the other day, I had someone ask me where I live. And they were like, “No, where do you really live” kind of thing. Like just “Melbourne” wasn’t good enough for them. So, I mean I guess I’m really mindful of where I post pictures from so I don’t identify my suburb where I live. But then there’s things like choosing the battles to get involved in, and that can be really hard because there’s stuff that I wanna say that I’m just like, how much energy will this take?

And a while ago, about three months ago, I was involved in this ridiculous media situation in Australia where a very well-known, very high-profile journalist on our public radio station suggested my face would be good at Halloween and said a whole heap of other stuff in this interview. And I tried to remain professional and polite in the interview, and I don’t think he or the producers picked up that I was quite uncomfortable because I just felt like I had to be the nice person, you know, be professional. And afterwards, a friend, Jessica Walton—you know Jessica—she tweeted, she live-tweeted the interview when she was listening to it. And then it went viral because of that, and that was good because so many people realized the ableism and realized the inappropriateness of his interview. And then the next day, it made national news, and my phone wouldn’t stop ringing. And probably eight articles were written about me, and I gave two interviews. I gave one to a newspaper that I trust, and I also gave one on TV, so I was on live TV. And my decision not to read any of the comments on the Facebook post saved me, I think, because I was oblivious to what people were saying. Because constantly, you get the devil’s advocates that are talking about, “Oh, maybe they meant it this way. Maybe they didn’t mean it. She’s just being too sensitive.”

ALICE: Mmhmm.

CARLY: So, not reading the comments was a good thing. And I think where I have been in the media, I’ve read a lot of the comments, and that just infuriates me. So, I think in the future, that’s what will happen. I will do that unless someone tagged me in there. I even ask people. I think I even ask people, like don’t let me know what people are saying about me.

I think there's also the [chuckles] the difficulty—and I've definitely felt this, and I've talked a little bit about this to you—of losing friends because we have different viewpoints or different work paths or whatever. And that has been extremely hard in the last year where, particularly from disabled people. And my view is there's enough pie for all of us. If I have made it on social media through really hard work and constantly showing up, there's room for other people to do that as well. And just because I'm writing a book or just because I've got a speaking agent or doing speeches, it doesn't stop anyone else. In fact, I will amplify people's voices and pass on opportunities to people. But just because I'm doing it doesn't mean someone else can't and doesn't mean someone should stop talking to me over that.

ALICE: Yeah. I totally agree with that because it makes me really happy to see the success of others in our community, and that's really what it's all about. And I feel like this is a function of internalized ableism where we feel like we don't deserve it all and that we only get the crumbs and that we have to kind of fight amongst ourselves to be seen as the disabled leader or whatever you wanna brand yourself, right?

CARLY: Yeah.

ALICE: And I think again, it's about that whole outward-facing how are we viewed by non-disabled people? Which again is centering them. And I think that's really sad that there's such destructive kind of dysfunction sometimes that does happen. There's always pettiness, jealousy, competitiveness, and I think a lot of that is a function of how we grew up and the environments we're in, in terms of internalized ableism as if we can't make space for everyone. Which is bullshit. All of our success lifts all of us up, you know? At least that's what I think.

CARLY: Yes. Keep that line in: "All of our success lifts all of us up." You're right. I mean I know that through me telling my story, other people have told me that they're more comfortable to tell theirs. Now, that doesn't necessarily mean they're more comfortable to talk to the media. I know people that have said, "I haven't told my partner about my ichthyosis, and because of you, I have." Or "I haven't worn a summer dress for years, and because of you, I have." And that is a big thing.

ALICE: It's a huge thing!

[upbeat music break]

Say Hello, Carly's memoir

ALICE: So, tell me a little bit about your memoir because your memoir is titled *Say Hello: How I Became the Hero of My Story*. And it's gonna be published by HarperCollins. And tell me where you are right now in the writing process.

CARLY: Yeah. Well, it's been a difficult time. I mean the writing, writing the book itself is huge. Like it's just—I thought—Before Stella Young died in 2014, I had a chat to her, and she was saying that she was writing a book as well. That hasn't, I don't believe her book has come out. I'm not sure where she was up to with it, but I would love it if we could read a book of hers posthumously. But she told me that she's been given the advice that she could just write a whole heap of different essays and put them together. So, of course, Stella's one of my heroes. And so, I just went up Stella's path thinking, oh, I could just write a bunch of essays. It'll be like writing a heap of blog posts and putting them all together. It is not like that. You have to have some sort of narrative story arc. I'm so used to writing smaller pieces for the media. I find writing a 600-word piece really hard. But I can comfortably write a 1,000-1,500 piece. But this is huge.

And so, I did my first draft last year. I probably took from May to November. So, that's six months, but I don't really think I took all that time. 'Cause I was working. I had a part-time job for some of it, and I really only probably did it constantly, like really focused, for about two months where I was writing every day. And that brought it to 84,000 words, and I submitted it. And then I got the edits back in February, and it's structural edits. So, I'm gonna have to take everything that I'd written and reorder it and then rewrite some stuff and take stuff out. And so, it was nothing like writing a series of articles and putting them together.

And on top of that, I've got the emotional stuff, the exclusion and isolation, and it's a very lonely road. I guess I haven't—to be honest—I haven't had a heap of trauma in my life. I haven't had a heap of emotional trauma. Things have been really hard, but I feel quite resilient. And drawing of the memories, that can be quite hard. But then I just think oh gosh, I don't want it to be a whole sob story. I don't want it to be a winge, and I also don't want it to be inspiration porn. So, it can be really tricky, that balance. But I think the loneliness of writing a book is probably the hardest thing, where last week, it was a long weekend here, and I spent five days writing or not writing, procrastinating, and I didn't see anyone really except for my husband. And it was really isolating, just writing. And then you don't know if it's gonna be good, and I don't know if anyone's gonna read it. There's that pressure. [laughs] You know, it's so weird!

There's been a few times where I've rang the publisher going, "I can't do this. I don't think I'm the right person. Would you like me to give you the money back," kind of thing. So, that's been tricky. The self-doubt has been huge.

ALICE: And I'm guessing that it's really you against yourself, really, when you're writing.

CARLY: Yeah.

Working with editors

ALICE: And there's a lot of input from your editor. So, I was wondering what it's like working with your editor, and what do you think are the hallmarks of a good working relationship with an editor? Because obviously, that's really gonna make a huge difference in the way your book looks.

CARLY: Yeah, absolutely. Yeah. So, when I— So, at HarperCollins, there's a senior publisher that was working on the kind of getting my contract done, and then I sent the final first draft to her. And then she sent it on to an editor, and this woman is like a senior editor in the non-fiction department. And I don't believe that both my publisher and editor have a disability. I don't think they do. But I had to trust that they would get me. And when I got my edits back in February, I was like, "Fuck yeah!" You know, I said that because it was so amazing: she got it! She was suggesting things, like she suggested that I have to put a chapter in about why I don't want this to be inspo porn. She suggested that she wants to know more about how I feel when this ableist stuff happens to me. She really knew me. It was really great. She really, she was very sensitive and very empowering. And compared to working with a news editor who is so pressed for time, we don't talk on the phone. I don't even know some of my editors' phone numbers. It's very quick. This is very dedicated. We've had meetings in person. We've had phone calls. I've called her. I've cried on the phone to her. It's been amazing, and I'm really thankful that they get it.

I mean I don't wanna give away too much, but there's this line. There's gonna be a chapter with just one line, and it's quite aggressive. And that was my editor's idea.

ALICE: That's great!

CARLY: Yeah. It was great, really, really good. And I think not only having read my manuscript, but I think she's really dug into what I've done previously. Because for example, she said, "There was a line that you wrote in an article for such-and-such publication. I'd really like you to go more deeper, go deeper into that." So, yeah. I think it's been a really nice experience. When the awful media stuff happened with the radio guy, my agent—it was funny—'cause my agent and I get along really well. I would say that we've really become friends now. And my agent texted me going, "Oh, Carly, what's your home address? We need to work out some stuff around lending rights." And I thought oh, I think I've already provided this information. But anyway, so I texted her my home address, and the next day I got home to a bunch of flowers. And I texted her back with a photo of the flowers going, "Um are these lending rights?!"

So, she'd organized with the publisher to send me a bunch of flowers to cheer me up after the stuff on the radio, and it was just really lovely. The relationship's really nice. Actually, they made some complaint. My agent made a complaint to the radio station on my behalf after this happened as well. So, the feeling of knowing that they've got my back is really nice.

ALICE: Must be great. And I think that really must give you some sense of security and encouragement as you continue to complete your book.

CARLY: Yeah, yeah. Yeah, I mean they wanna see you succeed because there's a financial gain for them. But I think it's genuinely, they wanna see you succeed because they're trusting you with your writing. So, yeah.

ALICE: That's great. And I think not all folks have that kind of understanding editor or the editor that really understands what they're going through. So, that's really lovely!

CARLY: Yeah!

ALICE: That's really lovely.

CARLY: I talked about that government website I used to write for, and there was a change of editors. And one of the reasons I stopped writing was because of this. I remember writing about how for me with my skin, it's really hard to be spontaneous because I can't just have a night out where I go out drinking and then flop out at someone else's house because I don't have enough cream with me, or I need to wash, you know? And anyway, I remember she came back with some edits going, "But what about those people that just can't do any of that, like can't even go out? You can't be writing a story and then excluding those people." And I said, "But no, I'm writing about my experience." [laughs] Yeah, it was really tricky. So, she just didn't get it, but these editors are amazing. And yeah, I really, really love them, so.

And also, another thing that I've found is like the local bookstore scene as well. So, I go into my bookstore quite a lot. I've got a few near me, and there's been a couple who've just been, "Oh, how's your book going? When are we gonna see it? Don't forget to let us know when it's out." And there's a really big one in Melbourne called Readings, and that won International Bookseller of the Year, I think, in 2017. And it's a really great bookstore. They're already talking about my book launch and what will happen with that.

ALICE: Oh, that's nice!

CARLY: Yeah, it's been really nice.

Wrap-up

ALICE: Well, I know I'm personally really excited about it, and I think about you, I think about other writers like Keah Brown, who's also—

CARLY: Oh, I can't wait for her book!!

ALICE: Yeah, I know. It's gonna be, yeah. So, it's really just an exciting time.

Thank you so much for being on my podcast today.

CARLY: No problem. Thank you for having me! I listen to it a lot. I listen to *Disability Visibility* a lot. I love it. There's a few disability podcasts that I love, and well, there's not many of them. Let's face it! [laughing] But I really like yours. So, thank you.

ALICE: Aw, thank you so much! I appreciate it.

[hip hop]

ALICE: This podcast is a production of the Disability Visibility Project, an online community dedicated to creating, sharing, and amplifying disability media and culture. All episodes, including text transcripts, are available at DisabilityVisibilityProject.com/Podcast.

You can also find out more Carly on our website.

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Well, I'll see you sometime soon! Smell ya later. Byeeee!!

♪ ...in a minute I'll be on the next gimmick
Poopin' on a flex and goffin' off with sex image
Ass to the max yeah
Disconnect your booty
Ass go to max
You don't disrespect your duty
On the blacktop, catwalk, Colfax, wax on.... ♪